

'The family is part of the treatment really'

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“The family is part of the treatment really”: a qualitative exploration of collective health narratives in families

I. Introduction

Health professionals in primary care are increasingly being urged to ask about family history, and possibilities to use this information systematically to discuss illness prevention with patients are currently being explored (Qureshi et al., 2009). However, discussions about family history in a health care context can be problematic. Health professionals may focus on extracting numerical information and sideline contextual narratives. For example, in consultations about heart disease, general practitioners may concentrate on the number of affected relatives and how old they were when diagnosed, avoiding engagement with patients about why they thought their relatives had heart disease (Hall, Saukko, Evans, Qureshi and Humphries, 2007). Clinicians are increasingly asking questions about family history of illness, prompted by guidance (see e.g. *Joint British Societies* (2005)). The information they glean becomes part of decision making, such as the decision by the doctor to prescribe a statin to reduce cholesterol level in the blood and so reduce the risk of cardiovascular disease, while the patient’s understanding of their family history may influence the decision to take the statin or not (Frich, Ose, Malterud and Fugelli, 2006).

Qualitative research on the patient experience of heart disease in the family has shown that a person’s sense of family history may be complex and influenced by a multitude of personal and social factors. Davison and colleagues (1991) have described a ‘lay epidemiology’ of heart disease which focuses on individual characteristics and highlights the ‘unwarranted survivals’ and ‘anomalous deaths’ made invisible by a

simplistic application of the population model. Patients in a recent study talked about family members in terms of heart problems that were expected ‘a heavy smoker’; ‘quite a nervy bunch’, or unexpected ‘she is the fit, healthy one’ (Hall et al., 2007). Hunt and colleagues (2001) found that perceptions of having a family history of heart disease may be influenced by age, gender and class. The relationship between an individual’s perception of vulnerability to disease and the experience of illness in the family has also been studied in relation to other conditions such as breast cancer (Erblich, Bovbjerg and Valdimarsdottir, 2000; Rees, Fry and Cull, 2001). Walter and colleagues (2004) concluded from their meta-analysis of qualitative research that abstract risk is embedded within an experiential context which contributes to illness in the family becoming ‘salient’. Some of the emerging themes outlined by Walter related to recognised risk factors (number of affected relatives, their age at death, degrees of disablement). Others, such as similarities and differences with family members or closeness to the affected relative, were based on relationships within the family.

These studies, while allowing for complex and changing kin relationships, focus on the cognitive processes of the *individual* assessing their risk. However, sociologists have described how family relationships are collectively developed and negotiated through storytelling by and about family members (Mason, 2004). Collective family identities may be created through the laying down of memories attached to celebrations, family albums, and meaningful objects (Smart, 2007). These identities need to be maintained by ‘kin work’ which is traditionally gendered female (Di Leonardo, 1992; Gerstel and Gallagher, 1993). More generally, storytelling within families may celebrate ‘linked lives’ (Elder, 1994), and forge connections between

family members sharing character traits, personalities, or body types (Smart, 2007).

The discursive creation and development of a shared sense of embodiment and vulnerability is sharpened in families with a diagnosed genetic disease where a *collective* understanding of family risk may be formed through constant communication and ‘watching’ for the signs of illness (Featherstone, Atkinson, Bharadway and Clarke, 2006).

In this article, we explore whether the process of developing a collective understanding of medical family history occurs for people from families with more common conditions like heart disease, asthma or osteo-arthritis. Through in-depth interviews with lay people, we explore recollections of the family communication patterns through which family narratives about health are created, and the understanding of family health that emerges. By exploring these issues we also aim to increase understanding of what lies behind the descriptions of family illness that patients provide to clinicians. This may inform the development of clinical skills related to family history taking while also contributing to sociological thinking about collective family narratives by focusing on the health dimension.

II. Methods

This article draws on interviews with lay participants from an exploratory study aimed at finding out about definitions and understandings of ‘family history’ held by lay people and health professionals and their possible impact on the consultation.¹ We aimed at exploring the ‘deep background’ of what family history meant to people rather than focusing on an immediate health concern. Therefore, to avoid framing the interview within the context of a health care consultation, participants were recruited from the community (library reading groups and adult education venues in urban areas with differing degrees of affluence and deprivation).² As this was an exploratory study, we aimed to recruit 10 participants from different ages and socio-economic backgrounds. We did not aim to include ethnic minority participants as we could not do justice to the different set of issues related to family health in immigrant families (Burholt, 2004; Shaw and Hurst, 2008) in the confines of the study. Overall, 8 women and 2 men were interviewed; 8 were between the ages of 51 and 69. A student (24) and an older person (76) were purposely recruited to add perspectives from different age groups. One interview was discarded as the recording device had failed. All participants were White British; two had retired from manual/ retail occupations, one was a care worker. The others had a professional background (teacher; administrator; social worker). The lead author conducted the interviews from July 2006 to January 2007, using a semi-structured topic guide. Interviews took place at participants’ homes. While not in themselves following a narrative method, interviews aimed to elicit health related family stories about individual family members by inviting participants to retell conversations about family history and by asking whether they remembered repeatedly told ‘family stories’ about health or inheritance. We also tried to build up a picture of the context in which they were told. Interviews were

transcribed and entered into N-vivo for ease of retrieval; identifying details were removed and names replaced with pseudonyms. From a preliminary reading of five interviews, the authors developed a coding scheme encompassing both expected and emerging themes. Following the interview guide, themes were grouped into four main contextual areas (with this article focusing on the first two): 1) patterns of family communication about health; 2) the content of this communication; 3) views on the importance of family history for health and 4) experiences of discussing family history with health professionals. Some of the themes were expected in the light of the literature discussed above (e.g. importance of similarities between family members, ethical responsibilities related to knowing and passing on details of family history); others emerged from the interview data (e.g. the development of strong family ‘identities’ around a condition expressed by some participants; the dynamics of responsibility and caring developing around family histories). These emerging themes were in turn integrated into the interview schedule, and the coding scheme was applied with small adjustments to the remaining four interviews.

III. Results

1. Communication about health in the family

Within this contextual area, the main theme was the link between talking about health and family relationships overall, especially in demonstrating and fostering closeness and care for each other. This played out differently in participants' families. For example:

... whenever I meet big sister, the whole conversation is health ... mostly me asking her how she is and latest aches and pains ... but in a way it also gives me ideas, you know, what might be in store for me. [Heather (65, retired retail worker)]

Here, the younger sister demonstrated care for the older sister by allowing her to express 'aches and pains'. However, this was seen as a mixed blessing by the younger sister, as health dominated the conversation and could contribute to an obsession with illness:

I try to be positive but my older sister, I can cheer her up but she tends to be, doom...I don't want to be like that, no way am I going to be like that. [Heather]

This possibility was also raised by another participant who noted a discrepancy between the severity of health problems and propensity to talk about them:

Sister is suffering from kidney stones and other health problems, but does not complain about her health. The brother 'does go on' too much about health problems, although in R's opinion they are not serious. [Richard (69, retired manual worker), notes from interview]

In the following accounts, talking about health was linked to good family relationships and caring for each other (as suggested from phrases like 'family oriented' 'always on the telephone' 'very close'):

I'm actually an only child but we're very family orientated. In fact I've just come back from seeing my parents now, which I do every week. ... We do discuss... you know... health issues. We do talk about them quite a lot. [Christine (56, care worker)]

My sisters are always on the telephone to my mother or they're there ... so I think it's more that one person tells somebody else and then they pass it around, so it's just little bits that you mention in passing. [Joanne (55, administrator)]

Talking about health in the family also served to imagine possible futures, as the immediate experience of parents and older siblings served as clues of what might be 'in store for me' [Heather]. In Patricia's account, the father's early death was a regular topic of discussion among the siblings:

I have just been talking to my sisters. We're very close and we talk about... when are we going to die? [Laughs] We were saying, you know... if you've got some money go and spend it. You could be dead tomorrow. 'Oh I could be here for twenty years or I could be here for two years' and my father died quite young at sixty-two. [Patricia (60, social worker)]

For these participants, everyday talk about health was part of the social fabric of interaction between family members. This relates to the culture of everyday 'health talk' among women (often but not always related), allowing them to forge relationships while demonstrating care for the well-being of their families (Boneham and Sixsmith, 2006). Here, health talk was described as a sign of caring (asking about 'aches and pains', sharing bravado in the face of possible early death) but it could also establish the speaker's role as responsible for the well-being of others.

In the following, we explore the expressions of 'closeness' in more detail as it was a very important sub-theme raised by most participants. Coding for different kinds of closeness was developed from the detailed discussion in the first interview [Heather],

which will be described as a case study here.³ At first, she compared her own family to others where different generations live closely together:

We're not a close family like that, very spread out as well. My aunties and uncles are in Australia and New Zealand not just here in this country.

On the other hand, regular contact with relatives who were close by did not inevitably lead to strong emotional ties:

We're not what you call a close family, not... see them regularly but not that close you know?

The image of the 'close family' that formed the backdrop to these statements has been described in sociological accounts of the close knit working class family (and therefore may have resonated with Heather as her own family is working class), for example Young and Wilmott's (1957) groundbreaking study of families in the East End of London. Although phone calls now often replace frequent visits and joint activities (Lohan, 2001), close, supportive family relationships, especially between female kin, continue to fulfil an important function for working class families today (Mitchell and Green, 2002). However, Heather also described her relationship to older family members or siblings as less 'close' than her relationship with the next generations:

And with the children they sort of... if anything crops up they always say is there anybody in you know, 'did so and so have such and such?' ... because I am very close with my own children and grandchildren, very close.

For Heather, emotional closeness enabled openness about illness in the family, with her grandchildren voluntarily seeking out information. However, the link with family 'closeness' also situated health talk in the context of family expectations and obligations, where it might be expected even though possibly distressing.

Different aspects of closeness were also described by other participants. While the culture of health talk with relatives living close by was strong, several had family in other countries due to immigration (e.g. from Germany or Poland), or emigration (e.g. to Australia or New Zealand) and saw this as an obstacle to getting information about family health:

I think [mother] still has two surviving brothers who I haven't seen for a long time. My father still has two sisters. I believe one is in Poland and I think one lives in America but again I've had very, very little contact with them. [Joanne]

For relatives who lived in the UK, lack of geographic proximity could also lead to a lack of communication, especially when divorce and re-marriage complicated family relationships:

The twin sisters from my dad's second marriage ... one of them lives nearby just the other side of [Town], so I see her quite regularly. We get on well. The other lives further north, so I... we're kind of a classically fragmented dispersed family. [David (24, student)]

Another important factor described by participants was closeness in age: 'we [cousins] are not so close because I'm the youngest and there's quite a big age gap' [Christine]; "my aunt stayed quite close to us because ... she was only about eight years older than my sister" [Elizabeth, 69, retired teacher]. Some participants talked about older generations as more reticent about personal matters and more likely to suffer in silence. On the other hand, in several families, communication of health information centred on a woman of the older generation who had taken on a 'kin-keeper role' (Richards, 1997). Distances between relatives could be overcome by this

person acting as family ‘hub’, collecting and passing on health information for the rest of the family:

I think we’ve got one cousin who is like the ‘lynch pin’ and that’s actually Auntie [name] and she lives in Germany ... I don’t know what would happen if anything happened to [name], because I don’t know whether anybody else would tell us. [Christine]

Even though, as pointed out by Heather, regular contact was not by itself enough to develop health talk, it was an important prerequisite, especially between parents, children and siblings. Both Christine and Joanne were in regular contact with their parents; Heather and Irene said that their brothers visited when in the area. Contact with sisters was described as once a month (Heather) or regular contact by phone (Joanne, Patricia, Elizabeth and Florence). This regularity of contact enabled a steady flow of everyday communication about health, with ‘little bits mentioned in passing’ [Joanne]. Melanie Mauthner (2002) describes the importance of ‘friendship talk’ between sisters, cemented through confiding in each other. In this study, talking about health formed a strong part of friendship talk, ranging from casual enquiries to developing complex patterns of communication including several family members. On the other hand, failure to share serious health worries could make other family members feel excluded:

it’s quite a fairly touchy subject ... I think the only reason I found out [about a cancer scare] was because I was with [mother] at the time that she took a phone call on her mobile phone to tell her that she had the all clear. And I think if I wasn’t with her at that time she probably wouldn’t have wanted to worry me. She wouldn’t have told me this. [David]

The issue of not wanting to upset family members was also raised by Joanne and Irene who at times avoided talking about their health to their mothers as they knew they would worry, ‘doing the mother hen bit’ [Irene]. This pattern also emerged in

relation to the next generation, with women not wanting to worry their children and grandchildren with possibly inherited health problems: *“The [grandchildren] worry sometimes and say ‘we’re not very long lived are we’ [laugh] but I can quote some in their eighties and nineties.”* [Heather]

This connection between ‘health talk’ and family members caring for each other links to another important sub-theme, that of family members demonstrating care by encouraging them to take care of their own health. As described above, most of the participants said that their families talked about health a lot; the disconfirming case in this group was Irene, who at first said that her family did not talk about health at all. However, later in the interview she described her uncle suddenly ringing her:

‘because he has angina and other heart problems, he said “You need to get your cholesterol checked”’. This response could be linked to the moral obligation for family members to alert each other to possible inherited conditions created by the discourse of the ‘new genetics’ described by Finkler (2005). Other participants felt a duty to encourage family members to adhere to a healthy lifestyle, take medication, get tested for high cholesterol or support a family member coping with chronic illness by not offering inappropriate food; *‘the family is part of the treatment really’* [Christine]. Two participants (Christine and Patricia) saw their family as a ‘health-promoting family’ (Christensen, 2004) where encouraging others to live healthily or seek professional advice became part of regular health talk. This included informing family members of possibly heritable diseases:

I do try and tell my kids and I think it must be awful if you’re adopted and you don’t know that history, because there may be something very important that you could do something about it if you knew...you know...like breast cancer. [Christine]

From these accounts, communication about health in families emerged as desirable for health-related and social reasons. For some participants, ‘health talk’ with family members, especially siblings and parents, was part of everyday communication and required close contact, emotional closeness, caring and feeling responsible for other family members. While communication could be impeded by a lack of geographic closeness or lapsed contact, emotional closeness had a more complex effect and could both encourage and inhibit communication as not wanting to worry others could be an obstacle to talking about health.

2. Collective Health Narratives

In the previous section, we focused on the role played by ‘health talk’ as part of family communication. This section concentrates on the second topic area presented here, the content of this communication. Important themes in this area were descriptions of resemblance and dissimilarity (which were expected), and the emerging theme of family identities developing around shared health conditions which resulted in attempts to create meaningful links between the health of current and past generations. We begin by describing the participant’s accounts of collective understandings of family history. It is assumed that these were created and shaped by the health talk described above, but this cannot always be demonstrated with certainty. One area where several participants described family discussions of health and inheritance is that of resemblance which could be in traits and mannerisms as well as physique:

I have had that said about my grandchildren who get their words muddled up ... I’ve just remembered now that I never met my granddad, my dad’s dad but apparently he used to do that word thing as well. [Heather]

A strong element of stories about similarities recounted by our participants was that they were often stories of *dissimilarities*, with ‘odd ones out’ who are alike but unlike the rest of the family:

... there’s always a reference made to one of my sisters being exactly like my aunty basically because of the... even the physical appearance and also the temperament ... she’s very loud and one of my sisters is exactly like that. [Joanne]

This was played out especially in relation to weight: for example, Elizabeth described herself as fit and active, her sister and niece as plump and uninterested in sports; Richard pointed out the differences between his ‘skinny’ but hypochondriac brother and overweight but cheerful sister. Sometimes, this was expressly related to ‘genes’:

Well, everybody else is really skinny except for me and my aunty and they used to say ‘Oh it must be in your genes.’ I just think we’ve got a better appetite ... there was always the notion that we were similar and it gave us like a bond between us and we have a similar passion for things like cream cakes and stuff. [Christine]

An important aspect of Christine’s account is the linkage between family commentary (‘they used to say...there was always the notion...’ and the strength of the relationship between herself and her aunt (‘a bond between us... similar passion for things...’). However, being seen as ‘like’ a relative who died early could also be worrying to participants:

As a child I did link myself with my father [who died when she was very young] because I was being told ‘you’re so like him’ [...] I always aspired to that, to being like him, but as I grew up that left me and to me now I’m just my own person. [Irene]

I’ve been aware that my dad died at sixty-two and I was very similar in temperament, colouring, looks to my father, so I always have this thing; ‘Am I so much like him that...you know, genetically I’ve inherited that?’ [Patricia]

The stories about resemblance outlined above form a collective narrative ('they used to say it must be in your genes'), but they can be contested by the individual ('I just think we've got a better appetite'). This phenomenon of emphasising family relationships through 'resemblance talk' has been noted (Becker, Butler and Nachtigall, 2005). However, resemblances need to be recognised by other family members and may be disputed (Emslie, Hunt and Watt, 2003; Lawler, 2000) as they are part of the web of 'tangible affinities' that shape people's lived experience of kinship (Mason, 2008). Accounts from participants in this study created a complex combination of (assumed) genetics, mannerisms and temperament. They also link with research on perceptions of genetic illness risk which may be influenced by resemblance to other family members in looks and mannerisms (Richards, 1997; van den Nieuwenhoff, Mesters, Gielen and de Vries, 2007) As described by Shaw and Hurst (2008), our participants moved between the language of genetics (e.g. 'familial condition') and more holistic concepts of inheritance:

I had asthma; my elder daughter had it as a child. The gene, as we say now is there. We used to say, oh, it runs in the family. Whereas now we say, the gene is there [laugh] the typical gene has carried on. [Florence, 76, retired administrator]

However, there were also more general understandings of health in the family not directly related to resemblance. Various conditions (asthma, breast cancer, heart disease, thyroid problems, osteo-arthritis), and tendency to alcoholism, high blood pressure or becoming overweight were described as being 'in the family'; 'passing through'; there being 'a line of it' or 'coming from' one or the other side of the family. On the other hand, participants noted 'one-off' conditions that no other family member had and wondered why this condition had suddenly appeared or where it came from. Some participants noted general weak areas ('heart' or 'circulation'). For

example, Heather linked a complex array of similar but different health problems to more general family weaknesses that affected parts of the body:

Hearts things, breathing things; asthma, skin type things, Dad did have rheumatics so I don't know whether what I've got comes from there. We all seem... the three of us have got rheumatics actually but they haven't got what I've got. My sister has got angina, my brother has had open-heart surgery; I forgot to tell you that. I think it's hearts and skin and breathing.

From these patterns of similarities and dissimilarities, a picture developed of what the family was 'like' in health terms. This collective identity could be challenged or reinforced by interaction with health professionals. In Joanne's case, herself and two of her sisters testing positive for different forms of lupus made her suspect that lupus could be inherited even though health professionals told her it was 'just a coincidence'. On the other hand, Christine described the impact of living with 'familial' high blood pressure:

I was identified a few years ago with having... it's a familial problem. It's actually a familial high blood pressure problem ... So I actually went on to a course of beta-blockers and a calcium antagonist and also, just as a preventative measure, took Simvastatin, the cholesterol lowering drug, but I mean it wasn't that I was in any way ill. It was... you know... a preventative... because of the family history of heart disease and blood pressure in general. [Christine]

Later in the interview, she recalled having been diagnosed with high blood pressure at a routine health check after childbirth. However, her own diagnosis was woven together with her experience and family stories about heart disease (especially one uncle's sudden death at age 36), although her parents were still alive. She navigated a fine line between a new identity as 'a patient' (Getz, Nilsson and Hetlevik, 2003) and seeing herself as a healthy person who is not ill yet. She then integrated both by

describing herself as healthy for now *because* of medical intervention: '*because I'm being monitored I'm probably ... you know...a healthy person*'. The link between family history and a sense of the self as 'at risk' was also reinforced by the shared experience of medicine taking: '*I mean we all know what we're all on.*' For her, this collective identity foregrounded heart disease to an extent that it obliterated other possible health risks:

I think it's actually made me very complacent about things like cancer... Because there's no cancer in our family, no breast cancer ... I'm very naughty in that respect and I don't go for breast cancer screening because I think 'Well, it's not going to happen to me.

While these narratives were about recognised resemblances and shared conditions in the participants' family, they also described actively looking for similarities not previously discussed. In some families, this resulted in shared conditions such as an irregular heartbeat or underactive thyroid suddenly 'popping up' when a family member disclosed a health problem. However, this system could also lead to increased uncertainty, especially for those whose relatives were far away: they might have similar conditions, unknown to the participants. Likewise, when reaching back into the past, family stories became increasingly fuzzy:

My grandmother must have been born before 1900. There must have been elements of the family that the family history wasn't... you know... they just used to say 'She died young. Oh what a tragedy.' [Christine]

I would want to know [about possible heritable conditions] and I asked my sister and I said 'Well, what did my father's mum die of?' and she said 'Well, she was an invalid '... she was in what was then called a bath chair – a wheelchair, so I said 'Well why? What was it?' She said 'I don't know'. [Heather]

When family members extrapolated from the present to earlier generations, they were uncertain about whether the same conditions were present but not diagnosed, as health services had improved a lot since then:

We don't know that any of our parents were diabetic but then years ago they weren't so aware of things were they? [Heather]

I was sixteen when my gran died and to me, she was an old lady ... that was overweight and had bad legs and walked with a stick. Now she'd been doing that since I was a tiny tot. Had she got arthritis and nobody had diagnosed it? [Patricia]

Further back in time, participants had to rely on very vague and possibly exaggerated family stories: for example, Patricia recalled an unbelievable story of a great-aunt whose face was 'eaten away' by syphilis; two of Florence's uncles were miners said to have a 'weak chest', which could be interpreted as meaning heart disease, asthma or the effect of coal dust.

In contrast to these attempts to make links with the past through shared health conditions, cancer was a special case in that it was described as an aberration, possibly due to participants attempting to deflect its impact. Some described relatives with cancer as otherwise healthy (David's father survived prostate cancer, and Irene portrayed her mother's earlier health as good). Heather attributed her mother's cervical cancer to heavy smoking, while Patricia's family devised a complex system for keeping cancer at bay:

So, there are two grandparents with cancer. Our parents...my mum lived until eighty-eight and never, ever any sign of cancer, so we feel quite 'Oh it's not a genetic thing. It's not in our family.' [...] We haven't had any cancer in...you know, the other six...the six siblings around. One died but he was a publican and it's a well known fact that throat cancer and being a publican... Alcohol and smoking...it's...you know...a killer.

The prominent position of cancer in stories about family health, and the attempts to exclude it from narratives of inheritance could be explained by the enduring dread or stigma attached to it (Williams and Bendelow, 1998).

The accounts discussed here confirm earlier research about the importance of resemblance for family narratives about health. Several of the participants described a collective understanding of their family in health terms, with similarities and differences discussed and sometimes contested. For our participants, stories about similarities could work in two ways. Family members could link themselves to recognised similarities and health conditions seen to ‘run in the family’ (sometimes while acknowledging or seeking dissimilarity between family members). They could also actively seek out other family members with similar health conditions. However, when these family members were far away or had died, stories about them introduced a strong element of uncertainty and speculation.

IV. Discussion

This study drew on interviews with a small number of people; most were female and middle-aged. It did not contain perspectives from a minority ethnic background, which is an important limitation. Studies on genetic counselling in a variety of cultural settings suggest that there are similarities between the experience of White British participants and those from ethnic minorities, but there are also important differences. For example, British Pakistanis formed a hybrid discourse from the language of genetics and other explanatory models such as ‘blood’; ‘destiny’ or ‘God’s will’ (Shaw and Hurst, 2008), similar to White British people (Richards, 1997). However, in ethnic minorities, cultural norms such as gender roles or consanguineous marriage could also influence how genetics were discussed in families, whether genetic testing was sought and its results communicated to other family members (Raz and Atar, 2004; Shaw and Hurst, 2009).

Those that agreed to be interviewed for our study were interested in family health as they saw their parents age or their grandchildren grow up (see Backett-Milburn and colleagues (2005)); however, none described themselves as the ‘hub’ for family health information. While their demographics could be seen as reproducing normative roles of caring and kin keeping within families, participants had previously reflected on health and the family and thus provided rich data for this small, exploratory study. Another limitation is that family discussions still had to be inferred from individual accounts. Family group interviews could be a solution, but this study suggests that health stories are often exchanged on a low-key, everyday basis and this would be very hard to capture by a researcher as it occurs.

The culture of the ‘new genetics’, upheld both by the popular media and health promotion activities, implies that one’s life might depend on correct knowledge of one’s complete family history (Finkler, 2005). Biomedical and media discourses about risk factors therefore play a crucial role in shaping family narratives and communication, for example by creating pressure on people to ‘surveil’ themselves and their families by collecting and sharing genetic information (Bates, 2005). Participants in this study drew on shared experience, interactions with health professionals, and the language of genetics popularised by the media to create a shared understanding of family traits, strengths and weaknesses. However, in spite of the pressure to arrive at an agreed, ‘correct’ family history, uncertainty about these matters was a fact of life.

The stories told by participants in our study suggest the complexity of family health history. The majority were concerned about more than one condition. Some of these had a well publicised tendency to run in families (heart disease, diabetes); in others the evidence was less clear (osteo-arthritis, asthma, dementia). Collective family histories were created and circulated—especially between sisters—within cultures of ‘health talk’, and were contingent on family relationships, contact patterns and emotional ‘closeness’. There was slippage between words like ‘in the family’, ‘gene’ or ‘inherited’ and experiential knowledge was interwoven with expert discourse. Family stories about health offered a complex array of resemblances and differences that could be read as clues towards health in the future. These stories were sometimes linked to childhood memories of older relatives that offered tantalising glimpses inviting speculation about possible familial health patterns.

V. Conclusion

The family health narratives described by participants in this study are complex, deeply rooted and developed over the whole lifespan. From a sociological point of view, findings from this study relate to other research on the making and unmaking of relationships through shared or contested narratives. Like food, material objects, or secrets (Smart, 2007) medical histories are a medium to visualise and negotiate family relationships. For health professionals it might be tempting to cut through these stories to gather apparently simple information about family illness. However, our study explores how family narratives shape what the patient sees as important and what they communicate to the clinician. We suggest that clinicians need an understanding of what lies behind the information that patients provide about family health. Only through this understanding are they able to refine their communication skills for sensitively gathering information to inform decision making.

Notes

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² Recruitment, consent processes and interview schedule were discussed with the Warwick-Coventry Primary Care Research User Group and approved by Coventry Local Research Ethics Committee.

³ These three aspects of closeness, frequency of contact, geographical and emotional closeness which emerged from this interview have also been discussed in studies of family relationships (Bonvalet and Lelievre, 2005).

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